

Request For Proposal (RFP) 2007 Excerpt

4. Community Engagement Activities

Activities related to community engagement will continue throughout the Study. Once segments are selected (and to a limited extent prior to segment selection) Study Centers will conduct a number of activities to engage relevant local communities.

The NCS is committed to working with communities in an effort to improve the health of America's children. Although observational in nature, the study recognizes the need to involve both the national and local communities in planning and implementation. A strict community based participatory research approach is not possible for the NCS because the overall goals of the study were determined by the U.S. Congress in the Children's Health Act of 2000, and much of the planning for the study was completed prior to individual communities being selected nationwide as representative of U.S. births. However, principles of community-based research will be adhered to when feasible and appropriate. A partnership with each community should be formed to ensure mutual respect and the establishment of an ongoing relationship of reciprocity. A true collaboration between Study scientists and communities offers the hope of enhancing recruitment, retention, and participant satisfaction.

Ideally, Study Centers will be able to build upon prior networks and relationships with the local community. However, the unique sampling strategy, data collection intensity, and length of the NCS necessitate different approaches to working with communities than previous studies or projects. To build trust, enhance the credibility of the study and ensure community engagement on the local level, Study Centers will be expected to conduct a number of activities with and within Study communities beginning prior to initiation of enrollment and continuing throughout the Study.

Examples of ongoing activities include establishing a community advisory board, partnering with other organizations to host events or forums, incorporating community leaders into the Center structure, and building referral networks between the Study and organizations. Steps for community engagement will vary depending on the characteristics and experiences of the communities and the Centers, and it is expected that the most effective approaches will vary. Once data collection begins, communities will be interested in learning about study findings. Aggregate findings will be shared with individual participants and communities through newsletters, publications, and other means. The community perspective can inform NCS researchers on ways to be sensitive to unique cultural and political issues and concerns within each community when communicating results. Because the NCS is a long-term research effort, attention to sustaining community relationships will be of high importance.